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## **Testimony of Advocacy for Patients with Chronic Illness In Support of Raised Bill No. 368**

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Good afternoon. We appreciate this opportunity to submit written testimony to the Public Health Committee on Raised Bill no. 368.

Advocacy for Patients with Chronic Illness is a 501(c)(3) tax exempt nonprofit that provides free information, advice and advocacy to patients with chronic illnesses nationwide. To this end, we file free health insurance appeals on behalf of patients nationwide, including in Connecticut, and as a result, handle a large volume of medical charts each year. Based on this experience in reviewing medical records, we support Raised Bill No. 368, which would adopt an opt-in privacy policy for Connecticut's upcoming health IT exchange.

As you know, there are state and federal laws that require affirmative patient consent in order for certain types of sensitive health information – for example, mental health records – to be shared. These records cannot be segregated from other medical records, which is one of the primary reasons why it is necessary to adopt an opt-in policy for all medical records. For example, many patients with chronic illnesses also suffer from mental health issues, and this almost always is noted in their medical charts, along with a list of their medications, which also may reveal more sensitive information. An opt-out policy would place a significant burden on physicians to go through charts to separate out the sensitive information from the non-sensitive information, and, inevitably, mistakes would be made and there would be erroneous disclosures. However, the opt-in policy proposed by Raised Bill No. 368 would avoid both the burden of segregating records and the erroneous disclosures that inevitably would occur as a result. The only way to protect patients' sensitive information is to subject all of their medical records to the same opt-in procedure.

Moreover, in order to garner patient support for the health IT exchange, which is critical for its success, patients must trust that their most private records will be protected. If patients were to find out *after the fact* that their medical records already had been shared without their permission, they would not trust the exchange and the public's support for it quickly would erode. This would jeopardize the entire program. By contrast, the opt-in privacy policy approach to the exchange will enable patients to make fully informed and educated decisions about their participation and ensure that they trust the program. We know that this is the case because in the states that utilize this approach – which include New York, Massachusetts, and Rhode Island – experience has demonstrated that the vast

majority of patients agree to opt-in. Thus, an opt-in procedure would not undermine the viability of the health IT exchange; instead, it would reinforce it.

We fully support the establishment of a health IT exchange in the State of Connecticut that will protect its participants' privacy, as Raised Bill 368 proposes. The opt-in policy approach proposed by Raised Bill 368 not only will ensure that patients' sensitive health information will remain protected, but also will ensure the sustainability of the program by garnering the public's support and trust. Thank you.